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ABSTRACT

The proposed research design, to be actualized beginning in 1969, was evolved to determine the nature and prevalence of mental retardation in Canada and to relate them to other variables. Issues raised concerning both nature and prevalence were reviewed as were surveys in seven different geographic areas. A pilot study conducted in two small villages on Prince Edward Island produced an operational index of mental retardation and a research instrument including enumeration data, measures of intellectual and social competence, case histories, observation, and personality and attitudinal variables. Sampling procedures and field work plans were set; scoring, coding, and statistical facilities and techniques were fixed. (JD)

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MENTAL RETARDATION IN A CANADIAN PROVINCE

A Research Proposal

Report No. 3

C.W. Portal-Foster
Dorcas Susan Butt
Douglas Lloyd Tate
John Wayne Brighton

The Canadian Welfare Council
Research Branch
55 Parkdale Avenue
Ottawa 3, Ontario

April, 1969

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A

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C.W. Portal-Foster
Dorcas Susan Butt
Douglas Lloyd Tate
John Wayne Brighton

The Canadian Welfare Council
Research Branch
55 Parkdale Avenue
Ottawa 3, Ontario

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U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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Preface to Report No.3

This report on the study, Mental Retardation in a Canadian Province, is essentially a further issue of the research design, as submitted to the Department of National Health and Welfare, Ottawa, in December 1968. Sections of the original which are not pertinent to the purposes of the present report as a working document have been omitted.

It is hoped that the present report, when considered in conjunction with the two previous reports, will provide a worthwhile record of the evolution of the study.

PREFACE TO RESEARCH DESIGN

This document has been prepared for submission to the Department of National Health and Welfare. It is an application for support of the Canadian Welfare Council's study, Mental Retardation in a Canadian Province, and is the major research proposal.

Two previous reports on the study have been issued. The first outlined the elements of the research design and was an application for funds to carry out a feasibility study. The second was a progress report describing the development, design and execution of a pilot study in Prince Edward Island during the summer of 1968. The present report describes in detail the plans and procedures involved in launching and conducting the major study which, it is hoped, will begin in 1969.

The success of the study thus far has been due to the assistance and cooperation of many. Specifically, we would like to thank our consultants: Dr. M.N. Beck, Director of Mental Health, Prince Edward Island, has been a central figure in enabling the progress of the work. Dr. Joseph F. Jastak, University of Delaware, has been influential in laying the groundwork for the initial design. Dr. James Wanklin, School of Medicine, Dalhousie University has given valuable advice on sampling procedures. The final responsibility for the decisions, planning and interpretations rests, of course, with the authors.

We are indebted to Mr. Bryson MacDonald, Executive Director, Ottawa and District Association for the Mentally Retarded who assisted with arrangements for training the interviewers. Several families of the Association gave their time in acting as subjects for the training sessions. We are gratified by the cooperation and time given us by the two village communities in which the pilot study was carried out.

The staff of the Council was a continued source of support: including those who went into the field as interviewers, (Mr. Milan Meleg, Mr. and Mrs. David Strachan, Miss Judy McCann and Miss Janice Latimer) and our research and secretarial staff in Ottawa (Mrs. Connie Young, Mrs. Dawn Repath, Mrs. Beverley Macmillan, Miss Deanna Colby, Mrs. Marjorie Berry and Mr. Richard Cochrane).

Finally, we wish to thank the Department of National Health and Welfare for the financial support which has made this document possible.

I - STATEMENT OF THE PROBLEM

The problem of the proposed research may be stated in question form. What is the nature and prevalence of mental retardation in Canada?

In Canada, an estimated seventy-two million dollars per year is currently spent on the treatment, care and facilities for the mentally retarded. In spite of these expenditures, people working with or planning programmes for the retarded often question the overall goals in developing them and call for an increase in theory and research in the area. They frequently wonder if with gaps of knowledge surrounding retardation, especially in the socio-psychological areas, enough is known to plan and care for the retarded in the best way. Masland, Sarason and Gladwin (30) separate the medical and biological problems from the social and behavioural problems in approaching retardation. Albee (3) has pointed out that the majority of the retarded need rehabilitative training rather than medical treatment and that the overemphasis on bio-medical research stems from the misconception that mental retardation is an entirely inherited disease. Dingman (13) has also issued a plea for more retardation research into social and educational variables. The relevance of these variables is crucial in three ways. First, it is necessary to know what part social and cultural deprivations play in precipitating psychological states later called "retardation".

Second, given a state of retardation, it is necessary to know what its effects are upon the psychological life of the individual so described. Third, knowledge is needed on how the condition effects the retardate's family and the community in which he lives. Unless such issues are examined, it is very difficult to plan programs and facilities for the retarded with confidence.

Another major barrier to the optimal use of funds is the absence of statistical information on the prevalence of mental retardation in Canada. Many estimates have been made (32 p.3), however, these are usually based upon generalizations of prevalence from cases on record within a given area, or upon the application of a very general statistic, such as, that 3%, (1, p.53) of the population is mentally retarded.

The present state of knowledge surrounding the prevalence of mental retardation in Canada, is mirrored by the following quotation made in a report to the President of the United States in 1962: (1, p.29)

> ...No one knows what proportion of the nation's unemployed, out-of-school youth are mentally retarded or even how many were once enrolled in special classes. Of all aspects of the problem, that of provision in public institutions is the best documented by age, sex, degree of disability, and clinical diagnosis....

Considering that statistics based upon residential institutions make no allowances for replacement or recurring admittances; they may be judged unreliable estimates even of their own limited population.

They certainly do not allow generalizations to the total population of a nation.

In summary, calls for research in the field of mental retardation center around two major problems or issues which are inter-related. The first is the problem of definition and effects. In diagnostic terms, 50% or more cases of retardation are diagnosed as functionally retarded or of unknown psychogenic origin (32, p.14). For too long, retardation has been approached as separate from the social structure in which it is found; thus the first problem involves further definition of the concept in terms of the relationships between relevant physical, psychological and social variables.

The second issue which calls for research is that of prevalence. There have been no prevalence studies carried out in Canada in the field of mental retardation. Some prevalence investigations have been done in the United States (and these will be reviewed in a later section) but, even if it is assumed that the Canadian and American cultures are highly similar, comparisons or generalizations to Canada are tenuous. Previous surveys in the United States have covered small areas such as Onondaga County (33) in the State of New York. In Canada, the occurrence of mental retardation by sex, age, income group, ethnicity and degree of disability is unknown. One need not go far to hear of cases by word of mouth where children, especially in rural areas, live their lives from day to day with some gross physical, mental or social disability with minimal professional help - or without it.

The present study is proposed with the belief that until information is available and interpreted to answer the preceding questions, programmes and facilities cannot be planned or provided in the most efficient manner. Neither can they most effectively answer the needs and enhance the everyday lives of the hundreds of thousands of individuals which they must serve.

II - PURPOSES AND SIGNIFICANCE

The general aims of the project were presented in Section I. Section II enlarges upon the aims by describing in detail the major issues raised under the general problems of the "nature" and the"prevalence" of mental retardation. At the conclusion, specific problems are stated in the form of hypotheses to be accepted, rejected or reformulated on the basis of the observations made in the data gathering phase of the study.

A - The Nature of Mental Retardation

A study of the nature of mental retardation is, in essence, a reopening of Pandora's box. All of the problems which have complicated past research in the area come into focus: problems of definition, problems of diagnosis and measurement, problems surrounding the differentiation of mental retardation from other behavioural and psychological entities, and problems of making comparable observations across different social and cultural groups. Any attempt to define retardation necessitates stances on all of the above issues.

These difficulties have been sufficient to make some workers in the area deal only in terms of "behavioural problems". Workers in a treatment center for retardation may say - "Let us bypass all of the theoretical issues and deal only with behaviour. We will erase the offending behaviour by manipulating stimulus-response contingencies between the individual and those with whom he interacts."

Such a stance is atheoretical. It is the position of the extreme behaviourist who ignores theoretical issues and proceeds with the task of shaping behaviour.

Another method of lessening some definitional problems is by describing retardation in terms which are sufficiently flexible to enable a very broad definition. This permits fluctuation of the definition according to the environment and social structure within which they are being applied; for example, across age, social or cultural groups.

The American Association on Mental Deficiency (21,p.3) defines mental retardation as follows:

> ....Mental retardation refers to sub-average general intellectual functioning which originates during the developmental period and which is associated with impairment in adaptive behaviour....

This definition focus' upon a new dimension in the approach towards and the study of retardation - a social definition which emphasizes the quality of the individual's responses to his environment. Leland (26) gives a detailed resumé of this approach. It is a flexible definition of retardation which is dependent upon environmental demands.

Both of the above innovations contrast the classical medical definitions of retardation by emphasizing the social repercussions of disabilities rather than concentrating upon precise categorization in terms of etiology and the resulting syndrome.

Psychometricians provide another approach towards defining mental retardation. An individual is given a psychological test and, on the basis of his performance, he is compared with a nomative population and classified accordingly. The individual is defined as being retarded in terms of the degree his performance falls below a mean value. Those individuals with test performances one or two standard deviations below the mean may be called retarded depending upon the purposes of the assessment.

Four currently used approaches towards the problem of definition have been mentioned: the behavioural, the social-adaptive, the medical and the psychometric. Since the behavioural approach essentially ignores definitional problems: only the medical, psychometric and social will be discussed further.

These approaches (medical, psychometric and social) carry with them assumptions about the nature of mental retardation. The medical assumes that states of retardation may be clearly diagnosed and the physiological bases identified. The psychometric assumes all retardation will be manifest in the level of intellectual performance, while the social definition assumes that retardation will be manifest in the adjustment of the individual to the demands of society. The medical approach results in a more limited definition of retardation. The narrower or more limited the approach followed, the less the scope of the results will be for theoretical and definitional purposes.

The narrower the definition, the narrower will be the perspective, and the fewer types of retardation will be understood. Thus, the social-adaptive definition which is the broadest approach will include all of the cases included under a medical definition and all of the cases included under a psychometric definition to the extent that the social environment demands intellectual performance. In addition, the social-adaptive definition will include cases missed by the other two definitions where the individual's major problem is social impairment.

On the basis of past work in the field, it seems best to approach the nature of mental retardation as a multi-faceted concept which can be approached on many levels from different perspectives. The three approaches under discussion are illustrated in Figure 1.

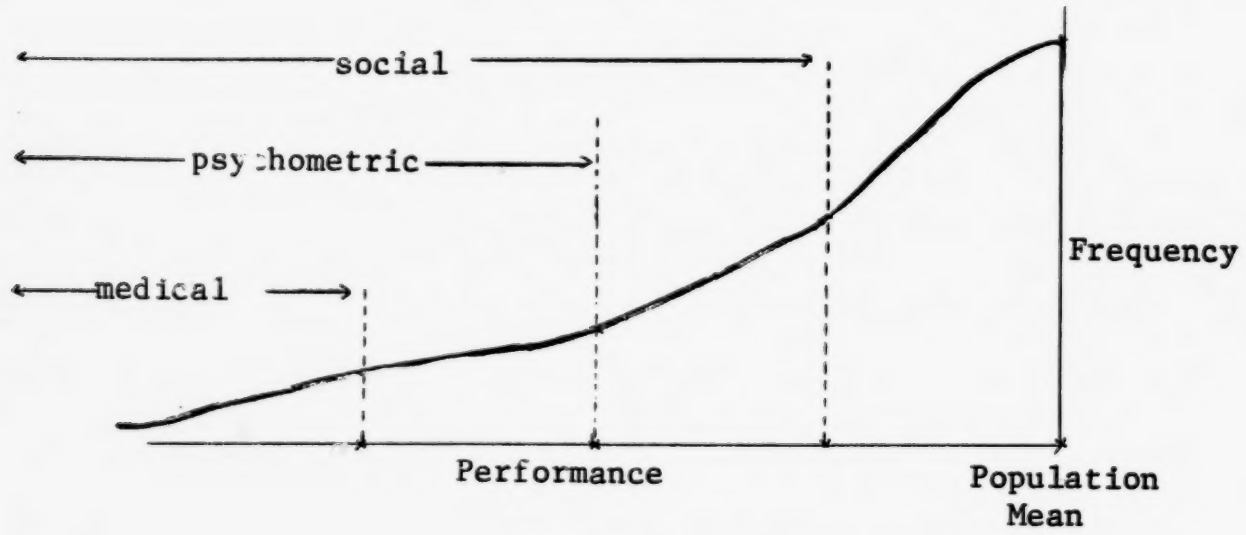

Figure I: Retardation: an hypothetical continuum showing the scope of medical, psychometric and social definitions in terms of the number of cases included in each. This model does not imply that a medical definition ignores social and psychometric criteria. However, in terms of the ultimate number of cases usually defined and accounted for, the above model applies.

We may assume that at the lower end of the continuum, the etiology of the conditions is more readily detected than the etiology of conditions closer to the population mean. A number of investigations illustrate that there are different etiologies associated with mild as compared to severe abnormality. For example, Wildenskov (41) divided mentally deficient patients into mild and severe groups and found that, in the mild group, subnormality existed in 51% of the siblings, but in the severe group, in only 26%. The studies of Bradway (6), Halpern (19) and Roberts (37) show that mild cases of retardation tend to come from the low socio-economic levels while severe cases tend to come from the socio-economic population at large. The more limited the definition, the simpler will be the task of identifying retardation and of defining its etiology.

However, since simplicity and ease are not necessarily desirable when dealing with the human condition and seeking understanding of it, the present study will proceed with a broad definition of retardation. This will be based upon an index combining measurements from psychometric performance, reports of adaptive behaviour, life history information and other data collected by interview methods. These are being used in order to arrive at a comprehensive working definition of retardation. Thereafter, types of retardation, degrees of retardation and the constellation of variables associated with each can be enumerated and described.

Retardation will be examined in relationship to the existing social structure. Such an approach has been called for by numerous authors such as Leland (26); Dexter (10,11,12) and Mendelsohn (31).

When taking a social-adaptive approach, a study cannot ignore the inter-relationship between the individual and society. Thus the effects of retardation upon the individual, group and community in which he exists will be studied. A number of social and psychological variables will be examined which may be preconditions to or which may result from the retardation.

There are several important factors to be investigated under both of these relationships (for example, social and personal values). Cultural and social deprivation are becoming increasingly suspected as leading to retardation. The study of the social and personal values of the communities and the significant figures in the suspected retardate's life may yield valuable information. Some forms of emotional maladjustment (such as anomie or delinquency) have been interpreted quite successfully as reflecting conflicts between the social goals held by most individuals and the social means, or the practical avenues of attaining those goals. Individual values have been studied by Hyman (23) as anchoring some individuals to certain social positions within a flexible system of stratification.

It would seem then, that the possibility of family values occupying a crucial place in the etiology of mental retardation is worthy of investigation.

Perhaps the cultural deprivation which results in retardation means simply that, although the external social goals and social means are available to an individual, he is deprived of the opportunity to develop the necessary values which would stimulate him to seek those goals. His motivations are the limiting factor. For example, in an area where book learning is minimized and the process of education is perceived as an irritant in life rather than as an opportunity and where the development of the self-concept is similarly uncared for, social retardation would be a probable outcome. If this is so, a comprehensive study must examine the predominant values and structure of the social system in which the retardate lives as well as the family structure and personal motivations of parents. These are crucial influences in the environment in which the retardate develops.

The effects of the retardate upon the environment in which he interacts is also related to a broad definition of retardation. In order to make recommendations on the treatment and care of all types of retardation, it is necessary to know how the condition is presently being managed and absorbed by communities, families, and the individuals themselves who are retarded.

The definition used, then, will be centered upon the social and psychological effects of retardation. For example, it would be useful to know whether families having a mentally retarded member in the home are more satisfied in their life experiences than those families whose mentally retarded member is placed in an institution.

Also, it would be useful to know whether the affectional levels of these groups are above or below the community at large and whether these levels are related to the degree and type of retardation. Preliminary data from the pilot study indicates that having a disabled member of the family may be associated with more frequent feelings of unhappiness but that the frequency of happy feelings is uneffected. Since these two dimensions of affect are uncorrelated one might conclude that the disability does not interfere with family happiness. However, the unhappy feelings and management of them should be the focus of study and management. These results are preliminary and need replication before definite recommendations for management can be made.

Attitudes are another important variable to investigate. Are the attitudes of the community and family members significant factors in the way the handicapped are dealt with in the community? And conversely, how is the treatment of retardates active in structuring those attitudes?

It is only through knowledge of such processes and interactions that recommendations can be made upon training, treatment and care.

B - Prevalence of Mental Retardation

The second major focus of this study is upon the prevalence of mental retardation in Canada. In order to understand the scope of the problem and to plan services in the future, an accurate estimate is needed of the number of retarded individuals to be expected; for example, in given regional, age, sex and ethnic groups.

Such studies are the only means by which efficient provisions for services can be made. They are essential so that the needs of different segments of the population can be met.

The major ecological variables to be investigated here are age, sex, region, the rural-urban continuum, socio-economic status, ethnicity, bilingualism, school facilities and predominant occupations and industries. Several of these variables have been suggested in the past through theory or research as being implicated in the etiology of retardation. A brief statement of past findings follows.

The age levels at which cases of retardation are identified depend upon the conditions and demands of the environment. For example, at the age of six, school demands may expose intellectual and social weaknesses which were not aggravated or particularly debilitating in preschool years. The number of recorded cases of retardation therefore usually increases until the ages of 14 to 15. At subsequent age levels the number detected typically subsides. There have been no definitive explanations for these trends. The speculations are that school demands and/or social interest may be lessened allowing the individual to settle into a social niche in which social and intellectual demands are few. For example, many retardates may fit into jobs as farm labourers or as household helpers. When old age is reached, the intellectual variable is still crucial. Recent studies have shown that when groups of aged people are given intelligence tests, longevity can be predicted from high performance on given subtests.

Those scoring poorly have a higher rate of death.

Studies have typically shown a higher frequency of retardation in males. This finding parallels statistics on medical, social and emotional problems in which male referrals outnumber females (33). The trends may reflect different environmental and social demands being made upon the sexes.

Regional variations in the prevalence of retardation are crucial in planning services and facilities and these are related to other ecological variables such as the rural-urban continuum. Several studies (38, p.16; 30, pp. 252-260) have reported greater concentrations of retardation in rural communities and several hypotheses have been offered as explanations. Some have suggested that many of the more intelligent individuals born into rural settings migrate to urban centers with the increasing urbanization of society. Others have noted the underprivileged status of most rural communities with regards to educational facilities and the appropriate socializing agencies to foster the intellectual and adaptive behaviours necessary to meet the increasing demands of a complex society.

Closely related to the above dimension is the socio-economic status of the parents of the retarded. The values of education and many types of intellectual pursuit tend to be fostered by parents of means. The lower socio-economic status groups have been shown in the United States to have higher rates of delinquency, psychosis, retardation and other diagnoses of social deviancy.

This is not true of all disadvantaged groups. However, frequently material impoverishment is accompanied by impoverishment of the proper conditions for social and intellectual development, impoverishment of access to treatment facilities, and most of all, in a society which values economic gain - impoverishment of self-esteem. The access of the poor to social services provided by a relatively prosperous and value laden portion of the population is receiving increasing attention and recommendations for change. Reissman (36) has recently compiled the literature in this area.

The different ethnicities of social groups have also been related to retardation. Social and technological developments in a given area may arise because certain ethnicities emphasize values in individuals which are necessary to achieve advancement. In other areas the predominant ethnic values may tend to produce more individuals with problems of adaptive behaviour because (1) the emphasis upon material gain, technological progress and human advancement produces additional strains, or (2) the values encouraged are not complementary to the prevailing social system with which the individual has to cope.

Bilingualism has appeared in the past literature (22) as a variable associated with retardation. That is, when a child is continually exposed to two sets of overlapping semantic stimuli in his early experience in the home and community, cognitive development may be complicated.

When a child approaches such cognitive stimuli and is expected to master and use two sets interchangeably, it may be that those children not equipped with average innate capacity, are pushed even further into a developmental sequence which is subnormal both in intellectual and adaptive maturation. As bilingualism is an important part of the lives of a large number of Canadian children, this is a variable worth exploring.

The school facilities within a given area play a major factor in the intellectual development and education of the surrounding population. Therefore, one could predict that the population living in an underprivileged area with regards to education opportunities will score less well on standard intelligence tests than a population which has had the opportunity to partake of a more developed educational system.

Lastly, the predominant occupation or industry of a population may affect the intelligence and social development of the people in that region. This is a complex variable which has not been fully explored in other studies. It has been noted by Tregold (38, p.14) that professional people have a lower rate of mildly retarded children than working people.

The foregoing variables are inter-related. Scoio-economic status, occupation, school facilities and certain types of ethnic value are correlated. The study will investigate and report the relationships of these variables to retardation but will not pretend to sort out the unique variance attributed by each to the retardation variable.

Such preciseness does not come within the domain of a survey. The trends noted may open up the way for smaller systematic studies in the future.

C - Outline of Purposes and Hypotheses

In order to summarize precisely the purposes of the study, the following section is included. The two major emphases are to describe and to explore thoroughly: the most suitable definition of retardation for a Canadian population and the prevalence of mental retardation in a Canadian population.

The following additional purposes may be stated, some of which lend themselves to further breakdown in the form of hypotheses.

(I) The Nature of Mental Retardation

Purpose 1: To arrive at a comprehensive operational definition of retardation in Canada, with sensitivity to (1) types of retardation and (2) levels of retardation.

Purpose 2: To differentiate and to specify the relationship between retardation and other forms of physical, personal and social disability.

Purpose 3: To investigate the relationship of retardation to other psychological and social variables.

Hypothesis 1: Retardation of the mild type will be associated with the personal and social values of significant people in the environment, (for example, parents, siblings and/or care-takers).

Hypothesis 2: Retardation of the mild type will be associated with the characteristics of the social system in which the retardate lives.

Hypothesis 3: There will be interaction between family and community attitudes towards retardation and the manner with which cases of retardation are treated. For example, in communities with accepting attitudes, the retarded will be kept in their homes more than in communities that tend to reject retardation.

Hypothesis 4: The personal characteristics of the family members having a retarded member will vary with the type of care given the retarded person, (for example, in the home or in an institution).

Purpose 4: To integrate the foregoing results and findings and to assess their significance in planning facilities and training for the mentally retarded.

(II) The Prevalence of Mental Retardation

Purpose 1: To estimate the number of cases of mental and social retardation per 1,000 citizens in the population specified.

Purpose 2: To estimate the number of cases of mental and social retardation within specified population ranges and specified ecological conditions.

Hypothesis 1: The prevalence of retardation will vary by sex and age. For example, males will have the greater overall prevalence in school years and beyond.

Hypothesis 2: The prevalence of retardation will vary across regional groups studied.

Hypothesis 3: The prevalence of retardation will be greater in rural as opposed to urban communities when retardation is defined psychometrically or in terms of intellectual and education performance.*

Hypothesis 4: Lower socio-economic status groups will have a greater prevalence of retardation than the upper socio-economic status groups.

Hypothesis 5: There will be ethnic factors associated with retardation.

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* This is an exploratory hypothesis within the context of the present study. It would have more pertinent application in other geographical areas of Canada.

Hypothesis 6: Families which are bilingual will have a higher prevalence of children who are retarded.

Hypothesis 7: Areas with underdeveloped educational facilities will have a higher prevalence of retardation.

Hypothesis 8: The predominant occupations or industries of regions will show associations with prevalence of retardation.

Purpose 3: To integrate information from all the preceding areas in order (1) to make recommendations on the planning of facilities for the care and treatment of the mentally retarded and (2) to make suggestions on how to maximize the personal development and self-fulfillment of retarded individuals.

III - REVIEW OF LITERATURE ON PREVALENCE OF MENTAL RETARDATION

Statistical information is available in many countries regarding the numbers of institutionalized mentally retarded. These statistics vary from country to country, and do not indicate the total number of retardates that exist in a given area. In order to determine the prevalence of mental retardation, population investigations have been undertaken. Such studies have attempted to provide quantitative information from which to estimate the size, nature and location of mental retardation, identify its component parts, locate populations at special risks of being affected and to identify needs for preventitive work, treatment and special services. It is hard to find two investigations in the literature, however, that are comparable in terms of diagnostic criteria, representativeness of samples or investigation methods. In general, previous surveys have been directed at single communities or small areas rather than large geographical entities. Although it is not possible to review all such community-diagnosis surveys, the most important ones will be chronologically summarized with respect to methodology and some of the data collected.

A. England and Wales (1920)

Lewis (28) conducted a survey of England and Wales and sampled six areas each with a population of about 100,000. He did not give the names of the areas and his descriptions of their general characteristics provides insufficient evidence from which to judge the representativeness of his sample.

For children, a screening device was used to locate suspected retardates. Teachers were asked to name the "most backward" children in their school and these children were then given a group test. Those scoring low on the group test were individually examined by Lewis or his assistant and were given intelligence and educational achievement tests, as well as a physical examination. Retarded children under school age were located through local mental deficiency authorities, child welfare clinics and district nurses. Possible adult retardates were identified by the "key informant method". That is, key people in each community (officials, teachers and social workers) were asked to name likely mentally retarded individuals. In addition, jails and mental institutions were surveyed. Suspected adult retardates were also given intelligence and educational achievement tests.

The criteria used were a combination of IQ scores and subjective judgements of social competence. Those with mental ratios under 20 were considered idiots. The imbecile category included those IQs between 20 and 40 as well as some between 40 and 45 who were judged as suffering from additional temperamental disabilities. The criterion for feeblemindedness was an IQ of between 40 and 60 The prevalence of mental deficiency (idiots, imbeciles and morons) was found to be 8.5%.

B. Baltimore Study (1936)

Lemkau, Tietze and Cooper (27) surveyed a residential segment of eastern Baltimore haveing a total population of 55,000.

Record searches were made of all community institutions and agencies concerned with mental hygiene and the basic data for the study was collected from these records. The prevalence of mental deficiency (defined by an IQ score of 69 or less) was found to be 12.2%

C. Onondaga County, N.Y. (1955)

A census (33) of suspected referred mentally retarded children under eighteen years of age was conducted by the Mental Health Research Unit of the New York State Department of Mental Hygiene in Onondaga County, New York. Individuals under eighteen years of age who were suspected ofbeing mentally retarded were identified by child-care agencies and various professional persons (103 schools, 494 physicians and 40 social agencies). Retarded and suspected retarded were identified on the basis of developmental history, poor academic performance, IQ score or social adaptation when contrasted with their age peers. This method was used after it was recognized that there was a variety of working definitions used by clinicians and social agencies and that mental retardation is not a discrete entity. The investigators believed that reporting errors probably involved more included false positives than excluded false negatives.

The overall prevalence rate for retarded or suspected retarded children under eighteen years of age was found to be 3.5%.

Prevalence was lowest for the youngest children and the rate for seven year olds was nearly seven times that of the five year olds - a fact which indicates the importance of school attendance in the identification of retarded children.

D. Three Scandinavian Studies (1951, 1953, 1956)

Three Scandinavian surveys carried out in the 1950's deserve brief mention. Bremer (7) conducted a five year study of a small isolated Norwegian fishing village consisting of 1,325 people. Diagnoses were based on information from hospitals, institutions, the child welfare council, as well as records of the medical officer, school physician and reports from public representatives and private persons. The investigator also acquired a thorough knowledge of the members of the community as he served as the local physician. On the basis of subjective judgements by Bremer and the school master, as well as school records, 5.6% of the villagers were diagnosed as oligophrenic. Book (4) invesitigated three large rural parishes in Northern Sweden (total population of 9,000) and found 4.0% incidence of mental deficiency (i.e. IQ less than 70). Essen-Möller's(15) sample consisted of 2,500 individuals living in two parishes in southern Sweden. Every person on the parish registers was interviewed and 1.0% were found to have IQ ratings under 70.

E. Delaware Study (1963)

Jastak, MacPhee and Whiteman (25) have reported on a survey of the population of the state of Delaware.

Their purpose was to explore the nature and psychological and social connotations of mental retardation in Delaware. A random sample of 1,000 family units was taken and each was given a screening interview which consisted of an enumeration of all those living in the household, recording of ages, sex, schooling, occupations, marital status and three subtests from the Weschler Intelligence Scale for Children. All members of families which contained at least one individual who obtained a WISC score at or below the 25 percentile were given a more intensive interview consisting of 15 psychological and 7 sociological tests and schedules. In addition, a number of non-retarded families were intensively interviewed as a control group.

In defining mental retardation Jastak et al. viewed it as a continuous theoretical construct. They operationally defined it on the basis of four indices: a psychometric average (comparable to IQ), psychometric altitude (highest subtest score), schooling completed and occupational achievement.

Three levels of mental retardation were defined. Those whose scores fell in the lowest 25% of their age group were defined as dull. If their scores were in the lowest 9% or 2% of their age group, then they were considered borderline defective or defective, respectively. This procedure did not ensure that 25% of the population would be defined as dull because four different criteria were used rather than just one. That is, for every 25 individuals diagnosed as retarded on the basis of IQ, only 5 were also classified as such on the basis of all four of the criteria.

Jasktak et al found that 2.0% of their population scored at the 9% level or less

Sex, religion, health, marital status, family size and parental age were found to be unrelated to retardation. However, in the 25% and 9% groups there were four times as many negroes as whites. The 4% of severely retarded group was more evenly distributed across race and economic levels. There was also a higher prevalence of mental retardation among unemployed and part-time workers as compared to other occupational groups.

F. Southern Swedish Study (1961)

Akesson (2) has reported a prevalence and genetic investigation in ten randomly sampled Southern Swedish rural parishes having a total population of 7,533. An individual was defined as mentally deficient when his rating on the Revised Stanford-Binet Test of Intelligence, Form L, Swedish version was less than -2 standard deviation units (i.e. IQ 68). Individuals rated -2 to -3 standard deviation units were referred to as "feeble-minded", from -3 to -5 units as "imbeciles" and below -5 units as "idiots". One hundred and thirty-two or 1.8% of the sampled individuals were found to be mentally defective. The distribution of mental retardation varied from geographical region to region, but was unrelated to parental age or birth order.

G. Imre (1967)

Preliminary data is available from an ongoing prevalence study of mental retardation in Rose County, Maryland (24).

The census included all persons between the ages of one and 59 years of age. A form was mailed to each household and was later picked up by a trained interviewer who edited the form and administered a modified Vineland Social Maturity Scale. Preschool children having a Social Quotient less than 80 were examined by a pediatrician and given an IQ test by a psychologist.

Adults who failed one or more items on the vocabulary subtest of the Wechsler-Bellevue I were administered four verbal subtests of the Wechsler-Bellevue Intelligence Test. The criterion for retardation for school age children was a Lorge-Thorndike group IQ score of 79 or less. In addition, teachers and administrators had the option of including any child about whom they had any suspicion of retardation. The children identified by three criteria were given the Peabody Picture Vocabulary Test and if they received an IQ score on this, they were also administered the 1960 version of the Stanford-Binet Test. The overall prevalence rate, to date, has been found to be 5.3%.

The fact that these community surveys differ in sampling, diagnostic criteria, etc. only reflects their different goals, circumstances and available tools. The question of what real prevalence of mental retardation is depends upon the use that would be made of such information. If the information is to be used to plan services then the severity of the handicap and its age distribution re-define its "real prevalence".

The above prevalence studies are summarized in Table 1.

TABLE 1

SUMMARY OF NINE PREVALENCE STUDIES OF MENTAL SUBNORMALITY *

Year	Location of Study	Investigator	Approximate Population Size	Source of Information	Age	IQ Range	Prevalence Rate/1,000
1929	England and Wales	Lewis	623,000	Register, Key informants, examined	all	70-0	8.5
1936	Baltimore, Maryland	Lemkau, Tietze, Cooper	54,600	Agency records	all	69-0	12.5
1951	Norwegian Village	Bremer	1,300	Key informants, examination	all	not done	55.6
1953	Northern Swedish parishes	Book	9,000	Key informants, examination	all	70-0	40.0
1955	Onondaga County New York	New York State Dept. of Mental Hygiene, Mental Health Research Unit	342,000	Agency records	under 18	above and below 90	33.2
1956	South Sweden	Essen-Moller	2,555	Examination	all	70-0	9.8
1961	Southern Sweden	Akesson	7,500	Agency Records, Key informants, examination	all	68-0	17.3
1963	Delaware	Jastak, MacPhee and Whiteman	220,000	Intensive interviews given to sample of 2,100	all	---	20.0
1967	Rose County Maryland	Imre	17,300	Interview	0-59	79-0	53.0

* Table adapted from a circulation of the Canadian Association for Retarded Children

IV - THE PILOT STUDY

During the summer of 1968, a pilot study was carried out in two small villages in Prince Edward Island. A full report on the execution of the study is presented in a progress report (34). There were three major purposes in carrying out the pilot work: (1) to test the theoretical stand taken in approaching mental retardation, (2) to arrive at an index of mental retardation, and (3) to test and develop practical field procedures.

The results of the pilot study have been essential in developing the research plans outlined in the following pages. Some of the results will be reviewed here for the purpose of leading up to the operational definition of retardation to be used and for the purpose of leading into the presentation of Section V, the Research Design.

A - The Population

The residents of two small Prince Edward Island villages made up the population of the pilot study. The total population of the villages was 610 persons. After attrition of the population due to age (under 2 years), illness, absence from the village (business, vacation, etc.), refusal to be interviewed and other unusual circumstances such as being in jail, the total number of people interviewed was 511.

The question, of course, immediately raised is: how many of the people not available for the reasons stated might be retarded? There is no reason to suspect that those individuals on vacation would have a higher rate of retardation than the general population in the village. Children under the age of two years who cannot be assessed other than through gross physical diagnoses would also not be expected to have a

higher prevalence rate of retardation. However, medical refusals and outright refusals may be related to certain types of retardation. For example, some elderly people had had strokes and were unable to speak. The outright refusals (16 in all) were often due to extreme negativism and suspicion, and a lack of social identification.

The following data, then, is confined to the testable populations of the villages studied In the study proper, data will be gathered from secondary sources on individuals who are unavailable. The secondary sources will be: reports from other family members, and from school and medical officers. A judgment will then be made of their intellectual and social functioning enabling their inclusion in the sample.

B - Measures of intellectual and social competance

Several types of tests and questionnaires were included in the interviews. Measures of intellectual and social performance are the only ones of interest here as they form the content of the "retardation index". The scales used are listed and briefly described below.

1. The Wechsler Intelligence Scales for Children (WISC)

Four subtests from the Wechsler Intelligence Scale for Children (40) were administered to all individuals five years of age and over. These subtests were combined into a total intelligence test score.

2. The Draw-a-Person Test (DAP)

This test (20) was administered to all subjects but was used as a measure of intellectual performance for those between the ages of two to twelve years only.

3. The Social Performance Scale (SPS)

This is a shortened form of Doll's (14) Vineland Social Maturity scale upon which mothers rated their children who were five and under.

4. Educational achievement (E-ach)

Two indexes were considered in assessing a person's level of educational achievement. The first, used for adults, was the last grade completed in school. The second, used for children attending school, was age minus grade. Adults who were illiterate and children who were not attending school were rated low on educational achievement.

5. Occupational Status (Occ-St)

A four point scale was used to assess occupational status. This reflects the degree of difficulty or challenge met by a person in filling a given occupational position. For example, a farm labourer receives a low rating while a business owner or highly skilled position such as a medical doctor receives a high rating.

6. State of Health (H-1, H-2)

Two items (H-1 and H-2) were included on the health state of the individual. One simply rated the state of health on a five point scale while the other was a checklist of five common complaints which are often symptoms of more severe physical disorders or of neurotic states. High scores indicate poor states of health.

C - The Mental Retardation Index

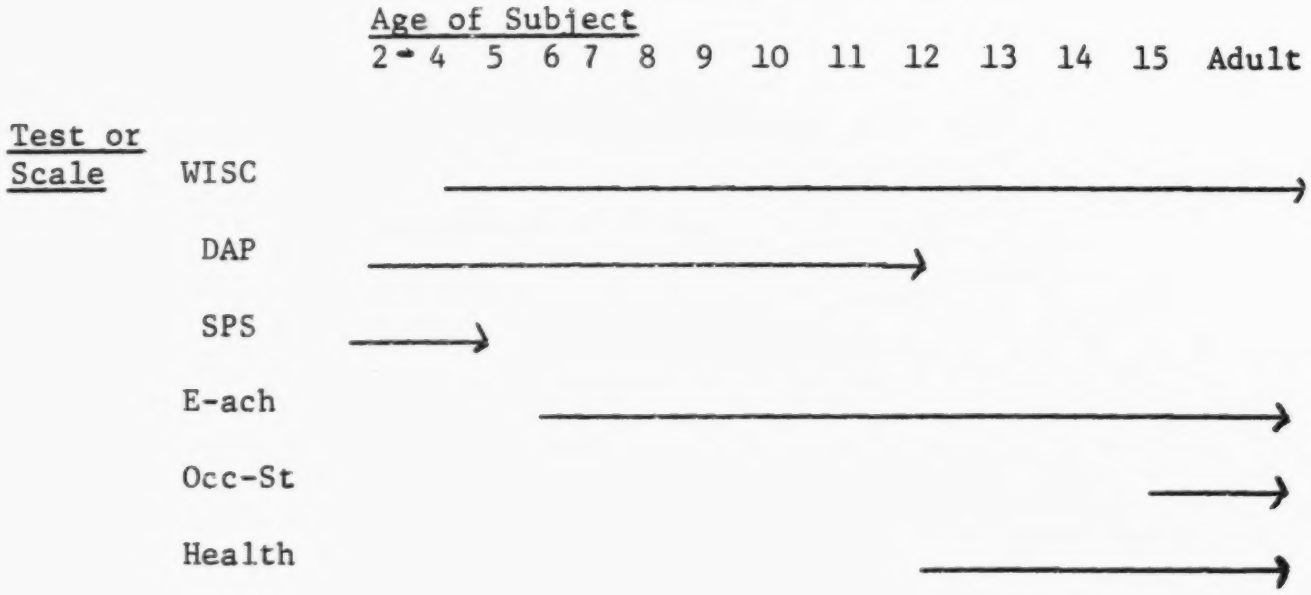
The mental retardation index determines which individuals are defined as retarded. It is based upon the above measurements combined into successive screening steps.

There are two methods by which retardation may be judged. The first judges the retardation of an individual by comparing his performance to those of others in the same age group from the same community. The retardation is judged within the context of the social demands placed upon any individual: how well does he measure up against his contemporaries? The second method of judging retardation is based upon a comparison of an individual's ability to perform up to a given standardization norm. In this case, the population for comparison may be considerably more distant than the one used in the first approach. To illustrate these two approaches - in the first, a 12-year old boy is judged retarded because he performs least well of 200, 12-year old boys who live in Prince Edward Island. In the second approach, 20 of the 200 12-year boys in Prince Edward Island may be judged retarded because they achieve a mean standard score of 7 (out of a possible 20 with a mean of 10) when judged against Canadian population norms.

In this study, retardation will be defined in terms of the subject's performance relative to other members of the community in the same age group. The comparison between members of the same age group will be made on the basis of several indices from different methods of measurement as indicated in the following table.

TABLE 2

THE TESTS USED AT DIFFERENT AGE LEVELS



D - Successive Screening Steps are used in order to determine if an individual falls within a general definition of retardation. After this, types and degrees of retardation based upon additional criteria may be enumerated. The order of the screening steps reflects the relative importance given the successive criteria. Thus the WISC score, when available, is the first and most important index. If a subject scores in the lowest 30 per cent of his age group on the WISC, the next criterion is examined. This might be the DAP. If the subject falls in the lowest 30 per cent of his age group on the DAP, then the next screening step is approached Education criteria are considered. One would predict that law scores on the preceeding intelligence scores would be validated by the educational, occupational and health criteria. The health criteria are the least emphasized measures in the retardation index because, in many cases, they may be a correlate of, rather than a necessary and sufficient condition for, retardation. However, one would expect it to validate the

preceding indexes in a majority of cases. That is, many cases of extreme mental retardation and of social retardation, will be accompanied by physical abnormalities or disturbances respectively. The development of the physical and mental structure of an organism cannot logically be separated.

Some of the requirements of the retardation criteria will be further refined before the final instrument is used. More information will be gathered from secondary sources as previously mentioned (school and medical officers). However, the data gathered in the two Island villages are sufficient to illustrate the use of the final mental retardation criteria.

The retardation indexes for different age groupings are as follows:

Age 2 - 4
(1) Subject's score falls within the lowest 30 per cent of the scores of his age peers on the Draw-a-Person Test.

(2) Subject falls within the lowest 30 per cent of his age peers on the Social Performance Scale.

(3) The mother's (or caretaker's) report indicates that physical or emotional development is delayed or impaired.

Age 5-12
(1) Subject's score falls within the lowest 30 per cent of the scores of his age peers on the Wechsler Intelligence Scales.

(2) Subject's score falls within the lowest 30 per cent of the scores of his age peers on the Draw-a-Person test.

(3) The subject's educational achievement is one or more years behind his age peers.

(4) The mother's (caretaker's) report indicates that physical or emotional development is delayed or impaired.

Age 13
plus (1) Subject falls in lowest 30 per cent of his age peers on the Wechsler Intelligence Scales.

(2) The subject's educational achievement in terms of present grade, last grade completed or literacy is below expectation. The "expectation" level is based upon the community in which he lives. For example, the average adult may have completed grade 8 and be literate.

(3) Subject is unemployed or, if he is employed, his occupation is in the operatives category (e.g., household workers, labourers etc.).

(4) Subject's physical and/or emotional development is arrested or impaired.

The retardation index reflects a series of successive screenings. Several types of retardation are involved: intellectual (psychometric) retardation, retardation in social performance, educational retardation, economic retardation and physical-emotional retardation or disability. All of these must be considered in arriving at a broad definition of retardation, and they must be weighted according to the demands of the social system in which they are applied. This weighting procedure will be carried out at a later date. Sufficient data is in hand from the pilot study to illustrate the use of the mental retardation index.

TABLE 3*

SUCCESSIVE SCREENING STEPS FOR YOUNG CHILDREN: EXAMPLES

S#	Age Yrs.	Mos.	Sex	Village	WISC	DAP	SPS	E-ach	Retardation
1	3	10	F	1	-	+	19	-	No
2	2	09	M	2	-	1	+	-	No
3	6	00	M	2	12	9	-	1	No
4	7	02	M	1	18	10	28	1	Yes

* For abbreviation symbols see page 29-30

The above table illustrates the use of the successive screening steps for young children. Where no data is available for an individual on a given variable, a "__" is entered. This occurs when the criterion does not apply in the age group to which the subject belongs. When a subject's score on the WISC, DAP or SPS falls below the 30 per cent cut-off, the score is shown. The 30 per cent cut-off for raw scores is calculated in terms of the area falling under a normal distribution curve. That is, all scores falling more than -.53 standard deviations below the mean are entered. Where the subject's scores fall above -.53 standard deviations, a "+" is entered.

In the last column of the table, retardation is judged "yes" or "no" in terms of the preceding data for each subject. For example, subject 1 is judged not to be retarded because his DAP performance is above -.53 standard deviation units below the mean. Subject 2 is judged as non-retarded because, although his DAP score is subnormal, his SPS score is not below the cut-off score for that criterion. Subject 3 is judged not to be retarded because, even though his WISC and DAP scores are below normal, he has completed grade 1 in school. Finally, subject 4 is judged retarded because on all measurements (WISC, DAP and SPS) his performance falls below -.53 standard deviation units below the mean score for seven year olds and he is behind one year in school grade completed.

Examples from the pilot study, of the screening process in adults, may also be helpful.

TABLE 4

SUCCESSIVE SCREENING STEPS IN ADULTS: EXAMPLE

S#	Age	Sex	Village	WISC	E-ach	Literacy	H-1	H-2	Occ-St	Retard-ation
1	61	M	1	38	7	No	2	1	4	No
2	42	M	1	45	5	No	3	1	1	Yes
3	34	M	1	62	6	Yes	2	2	1	No
4	47	M	1	33	-	Yes	3	1	1	Yes

This table illustrates the different retardation indices used for adults. Subject 1 is judged not retarded, as although his intelligence test score falls -1.40 standard deviations below the mean, and although he is illiterate, his occupational status is "4". As a matter of interest, this man is a prosperous farmer with an income of over $20,000 a year. He is not retarded in any area except "school learning" and thus is not included in the retarded sample. However, when retardation is broken down into various facets, and verbal ability is one of them, this man's illiteracy and low verbal performance will place him in that sample. It is this type of difference in definition that the study will be sensitive to. The implications of the different definitions will be studied. The over-all mental retardation index, however, does not classify this man as retarded.

In contrast, subject 2 has a low WISC score, and low indexes of educational and occupational achievement. He is, therefore, judged as retarded and is included in the retarded sample. Subject 3 is immediately dismissed from the sample because his WISC score is only -.13

standard deviations below the population mean for his age group. Finally, subject 4 is judged retarded because of his WISC score and low school and occupational achievement.

Two major points should be made with regard to the retardation index.

(i) A person is judged retarded in terms of his achievement on several different measures relative to other individuals who (a) are in the same age group and (b) live in the same social millieur.

(ii) Before an individual is classified as retarded, his original test protocal is examined, for information or alternating circumstances which would make the assessment of retardation inaccurate. This eliminates the chances of "false positives" occurring in the study sample.

On the basis of the retardation index, 72 of 511 persons in the two village populations (or 14.1 per cent) between the ages of 2 and 85 years inclusive, were judged retarded. This figure may be further broken down by age, sex, level of retardation and village community. It may be noted that the per cent of retardation identified is somewhat arbitrary and is related to the cut-off points chosen for the retardation criteria. Validation of the cut-off scores used, relates to the constellation of relationships which support them. When indices of low socio-economic status, the receipt of welfare payments, grade achievement and health correlate with retardation identified by a certain cut-off score, external validation of the operational definition is strong.

V - THE RESEARCH DESIGN

A - The Population and Location*

The population for study is the total population of Prince Edward Island. According to the latest census this is a population of 109,000. The smallest of Canada's provinces, PEI is located in the gulf of St. Lawrence between north latitudes 46° and 47°, and west longitudes 62° and 64°. The island is 120 miles long and from 3 to 35 miles wide, and has a total area of 2,184 square miles.

The population of 109,000 is about $5\frac{1}{2}$ per cent of the Canadian total. Prince Edward Island is the most densely populated province in Canada with a density of about 50 persons per square mile. Its population is fairly evenly distributed over the relatively uniform surface of rolling hills and farmlands. The major ethnic backgrounds of the people are: Scottish, English, Irish, and French. There are numerous religious groups, the major ones being Roman Catholic, United Church of Canada, Presbyterian, Anglican and Baptist. The major means of support of the people are agriculture, fisheries, tourism and some light industry. The average urban income for males in PEI is $2,934, while the average rural income is $2,152. For females the average incomes are $1,312 and $1,140 respectively. These are among the lowest in Canada. Unemployment reaches its peak in the winter and during the 1966 fiscal year 2,939 individuals were on welfare payments (39).

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* Figures quoted below are from 1961 and 1966 Canadian Census, Catalogue 92-602.

B - The Sampling Procedure

The sampling plan is to interview individually (unless age or disability makes direct interviewing impossible), approximately 1 in 22 people on Prince Edward Island. The expected distribution by age and sex for the resulting 5,000 people, using 1966 Census figures for estimates, would be as follows:

TABLE 5

EXPECTED DISTRIBUTION BY AGE AND SEX FOR A SAMPLE OF 5,000

	Age					
	0-4	5-9	10-14	15-19	20-65	over 65
Male	294	299	278	253	1121	253
Female	278	293	269	250	1067	278

If the sample of the population is further broken down into categories of expectation of retardation and degree, rather minimal figures result using the classical 3% prevalence estimate.

TABLE 6

EXPECTED DISTRIBUTION OF RETARDATION BY AGE AND SEX FOR A SAMPLE OF 5,000 BASED UPON A 3% PREVALENCE RATE

	Age						
	0-4	5-9	10-14	15-19	20-64	over 65	Total
Male	9	9	8	8	34	8	76
Female	8	9	8	8	32	8	73
Total	17	18	16	16	66	16	149

* The 3 per cent figure is used frequently in the literature. For example, the Federal-Provincial Conference on Mental Retardation uses a 3.265 per cent estimate (32).

If the major aim of the project were to study retardation in a classical, medical sense, then the expense and energy involved in interviewing 5,000 people to identify them would clearly not be justified. However, this is not the purpose of the study and the definition of retardation to be used is broader and more inclusive. Heber (21, p. 62) proposes a distribution in terms of standard deviation units based upon scales of adaptive behaviour and he (p. 61) states that the model may be applied to other measures which contribute to overall adaptation.

TABLE 7*

LEVEL OF RETARDATION, RANGE IN STANDARD DEVIATION UNITS AND PER CENT OF POPULATION INCLUDED -

Level	S.D. Unit Range	Percent of Population
Mild	-1.10 to -2.25	.1234
Moderate	-2.26 to - 3.50	.0120
Severe	over 3.51	.0001
	Total Per Cent	.1355

* This table was adapted from Heber (21, p. 62) with a slight change in standard deviation units in the mild range.

Using a broader statistical definition, 13 to 14 per cent of the population is of interest in studying retardation. The newest approaches to the problem of retardation tend to be of the latter nature. For example, see Jastak (25) and Leland (26).

Thus, in contrast to the above figures, the present study will focus upon approximately the lower 13 per cent of the population in question, resulting in the following expected distributions by level of retardation, age and sex.

TABLE 8

APPROXIMATE DISTRIBUTION OF RETARDATION EXPECTED, BY LEVEL, AGE, AND SEX IN SAMPLE OF 5,000 BASED UPON A 13% PREVALENCE RATE *

	Age					
	0-4	5-9	10-14	15-19	20-64	over 65
Male						
Mild	36	36	33	28	125	28
Moderate	3	3	3	3	11	3
Severe	-	-	-	-	-	-
Female						
Mild	33	36	32	30	128	33
Moderate	3	3	3	3	11	3
Severe	-	-	-	-	-	-
Total	75	78	71	64	275	67

* Estimates based upon figures cited in preceding page.

A random sample of the population of Prince Edward Island will be identified as follows: first a random sample of the surface area of the province will be chosen and those persons living in the sample area will be interviewed. Aerial maps of Prince Edward Island (scale 1/50,000 inches) have been acquired from the Department of Energy, Mines and Resources, Ottawa. The Mercator grids were numbered and using a table of random numbers, 306 grids (representing 5.83% of the surface area) were selected. The inhabitants of all dwellings shown in these areas will constitute a sample of the survey population approximately 1,225 dwellings and 5,000 inhabitants. Figure II illustrates the density of sampling.

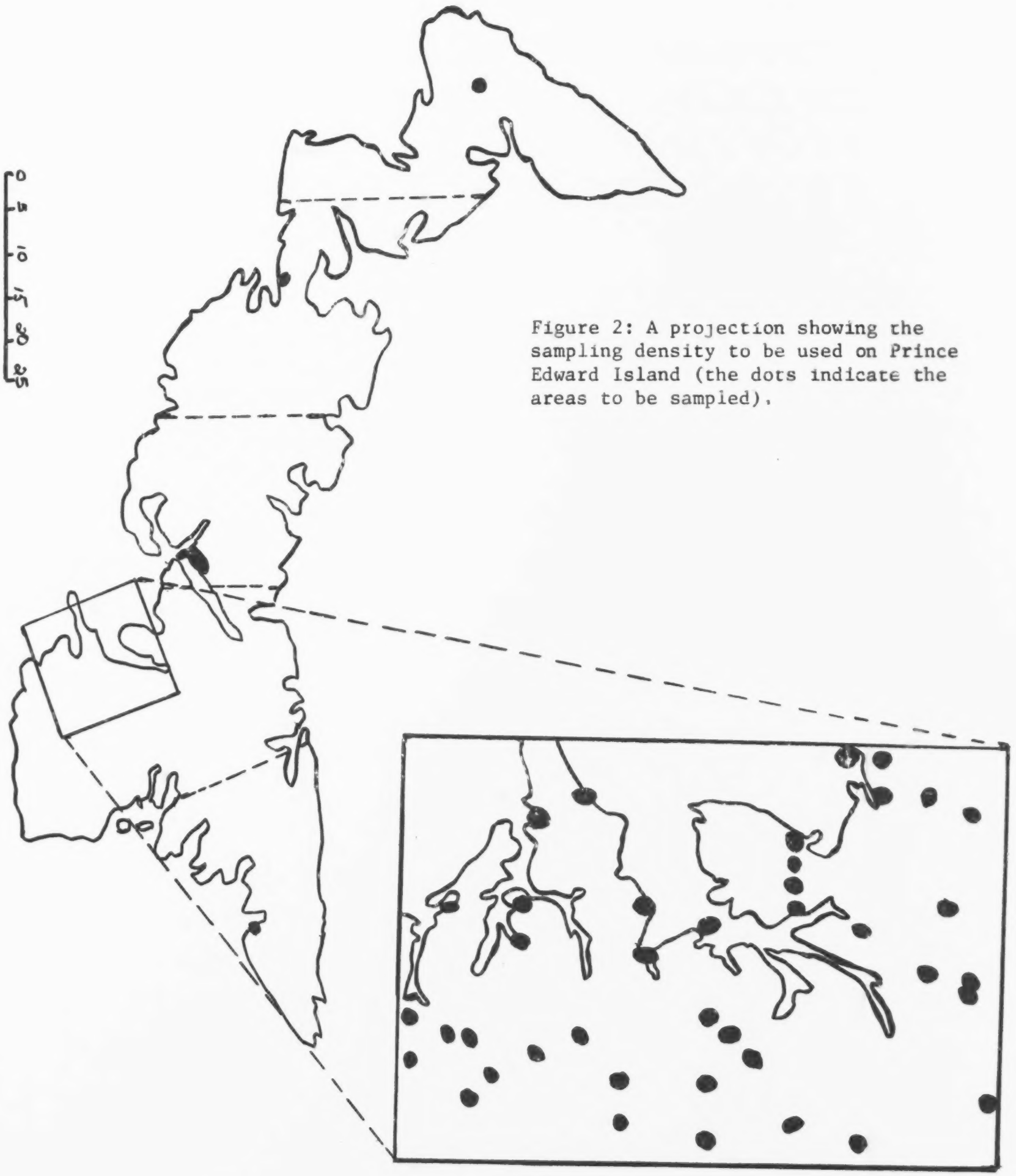

Figure 2: A projection showing the sampling density to be used on Prince Edward Island (the dots indicate the areas to be sampled).

C - The Research Instrument

A trial instrument was constructed for the purpose of the pilot study, and tested on an island population of approximately 600 people during the summer of 1968. On the basis of the trial run of the instrument, it has been modified and expanded where necessary.

1. Measurement Problems

There are three major problems which had to be met in the instrument development, one specific to the retardation variable and two applicable to the instrument as a whole These are: the transferability of the retardation definition across social groups, differences in the semantics used by subject groups and uncontrolled motivational variables within subjects.

(i) The Transferability of the Retardation Definition across Social Groups

Definitions of retardation have been closely related to intellectual performance and intelligence is a concern of the middle and upper socio-economic status levels of North American society. Therefore, the scales included in the present instrument must be sensitive to areas of performance other than those emphasizing verbal and school learning, unless the latter can be justified as being crucial in the expected life performance of all Canadians.

(ii) Differences in the Semantics used by Subject Groups

The instrument for use in the pilot study was written and constructed with the realization that there would be differences in language usage, vocabulary levels, symbols and

even physical stimuli common to given social groups. In spite of this the language used and phrasing of the questions was, in places, too complex for a large proportion of subjects to follow. In addition, some stimuli were simply foreign to the Island people. For example, one of the intelligence test items calls for a familiarity with umbrellas which Island people seldom use or even see. Careful consideration will be given to interpreting data which may result from variations in item difficulty levels across social groups.

(iii) Uncontrolled Motivational Variables within Subjects

Completion of the interviews and tests on the part of subjects necessitates focusing of abilities and motivation to do one's best. There is little that can be done when a subject is not cooperative or cannot focus on materials or try in the predefined manner. Examples of such variables are: a man not being sober at any time when testing can be carried out, or a child being so fearful that he will not leave his mother or even risk a performance on a test. These characteristics of subjects cannot be controlled. Optimal conditions can be encouraged and controlled to an extent by a skillful and experienced interviewer. But sometimes control of such variables is entirely beyond the scope of study when, for example, children in a slow-moving rather backward area are less highly motivated than children living in the middle of an urban center where

competition and speed are valued and encouraged.

One major strategy is being used in attempting to overcome these general difficulties. Whenever possible, more than one type of instrument or question is used to tap a given concept. In this way, the results will be sensitive to the issues described above and subjects will have more than one chance to demonstrate their performance level.

2. Content of the Instrument

The instrument itself may be described as falling into seven major sections. Subjects over twelve years of age answer a variety of tests and questionnaires. Subjects under twelve have fewer tasks, while subjects five and under have a limited number of tasks but information about them is gathered, in addition, from the report of the mother or caretaker. The seven major areas are as follows -

(a) - The enumeration data of households, families, individuals and their relationships.

(b) - The social performance in individuals

(c) - Measurements of intelligence and social maturity.

(d) - Life history information: past and present

(e) - Personality variables.

(f) - Attitudinal variables.

(g) - Assessment of the interviewee's behaviour during the interview.

The retardation index is computed from some of the foregoing materials (see pp.31-32). Each of the above categories of data will be described in more detail in order that the full background

and content of the types of data are made clear.

(a) - The Enumeration Data

In order for the study to be complete, comprehensive and replicable, all of the individuals in a given area must be tested or accounted for. As the initial sampling is done via aerial maps or buildings, the first task in the data gathering is to make a list of all households, families, individuals and their relationships to others occupying the same dwelling. Usually, the information is reported by the mother during the initial interview. When the information is not available in this manner, it is gathered from other sources in the community.

The enumeration includes a list of all individuals living in a given dwelling, their age and sex, the ethnic background of the family and the language(s) they prefer to speak in the home. When this information is gathered, families and individuals are assigned identification numbers. Complete master charts can be made of sampling grids, showing the dwelling units and listing each individual living within them - making complete replication of the study possible.

(b) - Present and Past Performance Indices

This group of indices contains a variety of information relevant to judging an individual's social competence. Some are gathered through self-report and others through the report

of major persons in the individuals' life. Included in these indices are: school grades achieved, ability to read and write, indications of any physical, emotional or intellectual handicaps, percentage of time adult subjects spend on government welfare etc.

(c) - The Measurements of Intellectual and Social Development

The major dimension of retardation, in spite of the new approaches to it, is still tapped by some index of the individual's capacity to perform intellectual and social tasks at increasing levels of complexity. Therefore, three widely used assessment procedures were used in the pilot study and will be employed in the major study for this reason.

(i) The Wechsler Intelligence Test Scores

The Wechsler Scales are widely used measures of individual intelligence in North American and other cultures and, consequently, much data have been gathered on their use for both clinical and research purposes. In the present study, two verbal subtests and three performance subtests from the Wechsler Intelligence Scale for Children (WISC) will be used for all individuals from five years of age and over. These subtests are comprehension, similarities, picture completion, picture arrangement and digit span. Since the first four subtests were used in the pilot study, considerable information on their use in a PEI population is available.

The question may be raised of why the Children's version of the scale is being used. The original Wechsler-Bellevue (W-B) scale, which was developed for use with adults, essentially became the WISC when a downward extension for use with young children was included. Thus, the W-B and the WISC have essentially the same item content. The Wechsler Adult Intelligence Scale was considered for use with adults, but discarded as: (1) being too sophisticated in item content for administration in rural areas of Canada and, (2) emphasizing accuracy of measurement at intelligence performance levels which are average or above. In the present study, accuracy of measurement is needed at the lower levels of performance.

From these scales, a verbal, performance and total test score may be computed for each individual. The scores for the subject population under study may be examined - (1) in relation to the island population and, (2) in relation to norms for a Canadian population or compared to the performance of other Canadian groups to be tested in later phases of the present study. The administration of these tests requires well-trained interviewers who are adept at encouraging ease and cooperation on the part of subjects, who are well practiced and skilled in the intricacies of the test themselves and who are careful in carrying out the clerical task of recording and scoring the subject's responses.

(ii) The Draw-a-Person Test

The Draw-a-Person or Draw-a-Man test has been widely used as a clinical research instrument in evaluating the intelligence and personalities of children. Schemes have been devised whereby the presence or absence of each part of the drawing, and the quality with which it is executed, is scored. The sums of such scores are used as final indexes of intelligence. Goodenough (17) and Harris (20) have proposed two widely used scoring schemes. This test will be used in the final study for the age groups of 3 to 12 and for suspected retardates.

(iii) The Vineland Social Maturity Scale

The Vineland Social Maturity Scale was developed by Doll (14) and has had widespread use in the assessment of the socially retarded; Leland (26). Doll's book on the development and use of the scale provides most of the necessary background information about its purposes, development and use. The interviewer poses in this test, a series of questions, to the mother of a child or caretaker who scores the child on 117 items designed to tap social maturity.

For the purposes of the present study, a short form of the Social Maturity Scale is being used. This consists of 36 items from the lower range of the scale upon which the mother or caretakers of children five and under, or, of suspected retardates rate their children.

(d) - Life Variables

The life variables in the study are direct self-report measures on a variety of content areas in a subject's past and present life. These range from essential facts such as age, sex, marital status, income and socio-economic status: to a series of questions on the subject's family such as sibling position, number of relatives living in the home, the kind of upbringing experienced and reading materials available around the home. Other variables tap: state of physical health, variety of daily public encounters, risk-taking tendencies and degree of church attendance. Some of the life variables contained in the instrument are included for the purpose of specific hypothesis testing. Others are designed for the primary purpose of describing the population accurately or have been included for exploratory purposes. Several of these items have been adapted from Glennon and Albright (16).

(e) - Personality Variables

Several personality variables are included in the questionnaire section of the interview to be answered by subjects 13 years of age and over. They include the following scales.

(i) Positive and Negative Affect: This is a short scale of ten items designed to tap the number of happy and unhappy feelings the subject has experienced during the last month.

The scale developed by Bradburn has been used extensively in survey type studies and the results have been reported by Bradburn in several publications (5).

(ii) Verbal Hostility

One of Buss' (8) short scales from his hostility inventory is included in order to have some measure of the expression of aggression in the individuals and families of interest.

(iii) Degree of Socialization

A measurement is included of the degree to which an individual has internalized common social values. A short form of a scale developed by Gough (18) and later included in the California Inventory of Personality was used. Gough developed the test empirically, that is, on the basis of whether items distinguished between groups predefined as socialized or undersocialized (for example, high school students and delinquents). This scale will be factor analyzed, thus individuals may be classified and compared on the basis of factor scores. One or more of the dimensions emerging from such a factor analysis would likely to be a significant factor in the attitudes towards, treatment of, and anticipated care of mentally retarded members of the community.

(f) - Attitudes and Values

Social cohesion is based upon shared attitudes and values amongst the members of a given community. Similarly,

it might be stated that individuality is based upon values or value constellations unique to a given individual. Thus, in approaching the treatment and care of retarded people, both social and individual attitudes and values should be explored. Items here include: general values in life, attitudes towards the disabled and retarded, and attitudes towards religion and the home.

(g) - Data on the Interviews

In order to adequately carry out the clerical tasks involved in the study and in order that the adequacy of the data be thoroughly evaluated, a considerable amount of information is gathered on each interview itself. The items included are completed by the interviewer and the interviewee. The former records whether the subject was interviewed, and if not, the reasons for the refusal and the steps taken in order to attempt to gain cooperation. The time and length of the interviews are recorded and a rating scale is completed on the subject's test-taking attitudes and test behaviour. The conditions under which the interview was carried out are noted. Finally, the subject himself fills out a six-item scale on his feelings when being interviewed; for example, did he feel interested or angry?

D - The Field Work

The success of the project depends upon the execution of a number of stages. One of the most crucial stages is the field work. The experience during the pilot project in two small P.E.I. villages has been invaluable in planning this stage of the project. The setting up and execution of the field work for the pilot project was so successful, that very similar procedures will be followed in the main study.

Much of the success in the field work, of course, depends upon the individual performance of the interview team members. Their success can only be ensured by careful selection procedures and intensive training which will be described in the following section.

The field work procedures are best described as a series of discrete categories which when executed, will fall into the overall process of data gathering. These categories are discussed under the following headings: the island, the interviewing team, the data collection and equipment.

1 - The Island

(a) Contacting Island Officials

We are fortunate in this project to have close contact with the Director of Mental Health of P.E.I. Because of this, we have access to many Island officials and leaders in all walks of life. The basic purpose of contacting the officials is both to explain the purposes and goals

of the study to them and to have them communicate the same to the residents of the Island. Any form of television and radio publicity given to the project will also be helpful and for this reason, contact should be made with the Island media before the project begins.

(b) The Sampling Areas

The sampling areas will be numbered according to interviewing sequences and the officials in those areas will be contacted about two weeks prior to the actual interviewing in the area. Priests, ministers, or other community leaders will be informed in detail of the project's value and their support solicited

The Island will be divided into five interview areas as figure 3 indicates

Figure 3 also shows the possible residential locations of the interviewing team members

2 - The Interviewing Team

(a) Living Accommodations in P.E.I

The interviewing team will consist of ten to fourteen members; they will work in pairs; two people being stationed at each of the proposed residential locations located in the preceding figure. Homes or cottages should be reserved in advance for the team members; that is, the project director or supervisor should precede the team to the Island and rent the accommodation. A roomy accommodation

PRINCE EDWARD ISLAND

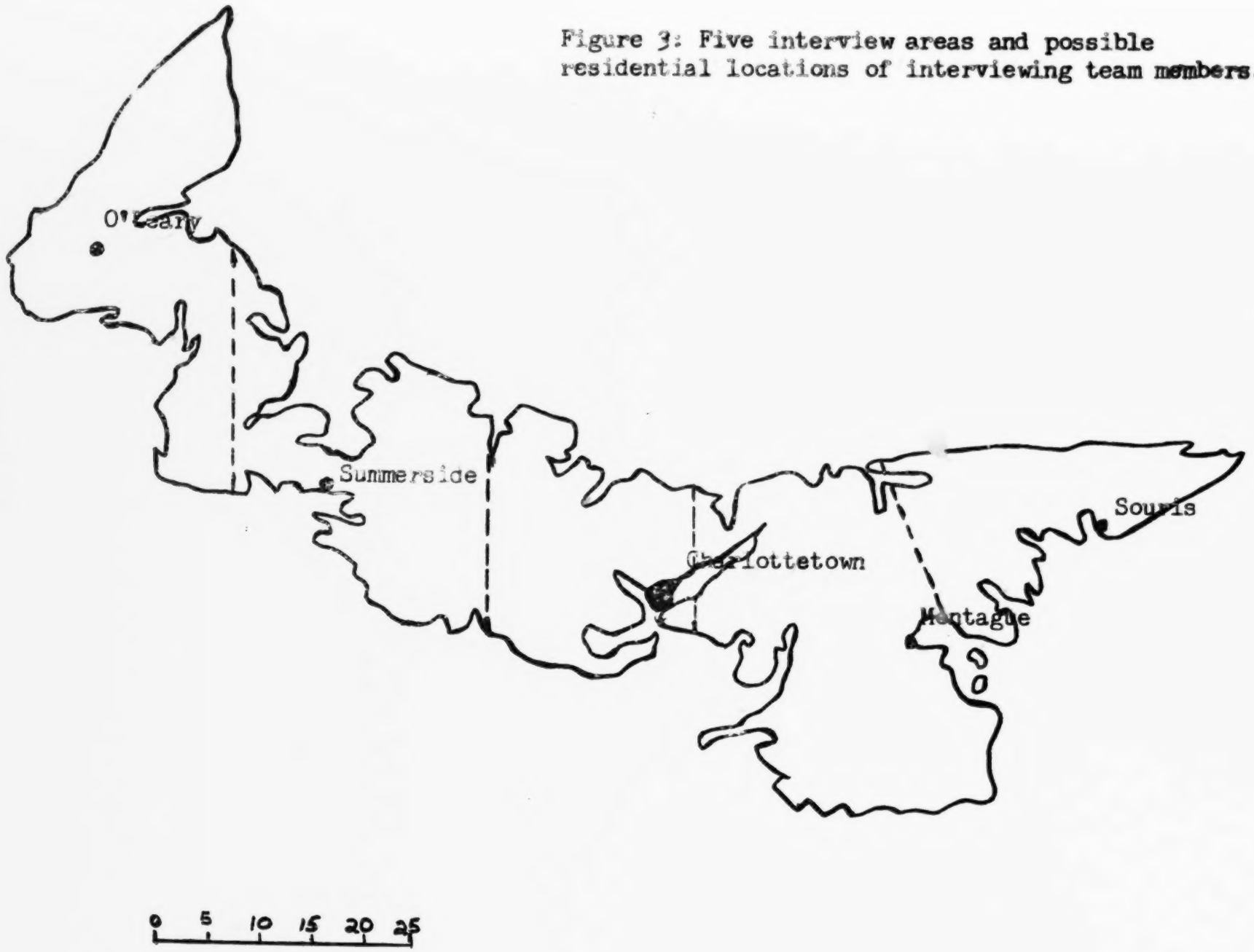

Figure 3: Five interview areas and possible residential locations of interviewing team members.

should be rented in Charlottetown to enable the housing of team members and supervising staff on occasions when the entire team must meet together.

(b) Supervision of Interviewing Team

An island supervisor will coordinate and direct the interviewing team members. This should be an individual of some maturity and experience. It is necessary that the staff have leadership at all times. The supervisor will be centered in Charlottetown, but will move freely in all areas. His main duties will be to keep work on schedule, to check the accuracy and quality of the data gathered, to see that records are kept complete and up to date, to deal with any social or personal problems arising in the staff, to act as a spokesman in dealing with general questions arising, such as the relationships with island officials, or rapport with island residences and lastly, to keep in close touch at all times with personnel in Ottawa.

(c) Morale of the Team

Care will be taken to ensure personal satisfaction among team members during the daily gathering phases. If the interviewers are not personally stable and at ease, they will not gather good data. There are several means by which morale can be encouraged and maintained, all of which will be used. Some of these are: by versing them

thoroughly in the purposes and the values of the work they are doing, by providing good leadership, by having frequent gatherings at a central headquarters for discussion and comparing notes, by hiring members in pairs (such as husband-wife teams, or good friends), and by encouraging friendly competition between the pairs.

3 - Data Collection

(a) Approaching the Subjects

The actual process of data collection is a crucial phase of the study. Contacting the people is, perhaps, the most important part of this stage of the project. Special care will be taken in all actions and behaviours associated with the islanders.

The people in each area will be given adequate prior notice that a team of interviewers will be requesting of them a short period of time in which to ask questions and administer an interview. Interviewers will always call at a house first, in order to arrange for a convenient time for the initial interview with the mother. Interviewers will carry with them an appropriate letter of introduction from both Ottawa and Prince Edward Island authorities.

On the basis of the pilot study most of the mothers and children will be interviewed during the day. Fathers will be interviewed during the evenings or on weekends.

(b) Refusals

In spite of the care in approaching the people, refusals will occur. In such cases, the individuals will be approached by different means, such as letters from Prince Edward Island authorities or by personal calls from supervisors. Every effort will be made to obtain the cooperation of such people; however, when this is impossible, the individuals will be assessed by indirect methods, such as through community schools and health records.

(c) Checks on the Adequacy of the Data

The flaws in the use of the interview as a method of gathering data in social research are well known. Maccoby and Maccoby (29) have given a comprehensive summary of this concern. In the present study, interviewer error will be kept at a minimum by three methods. First, a close check on the quality of the data gathered will be made. The supervisor will look out for sloppy or inconsistent recording which is often a sign of general weakness in the data. Secondly, interviewers will be encouraged to communicate any problems they are having with rapport, time-allotments and so on, so that they can be dealt with by the team as a whole rather than by an individual. Thirdly, identification with the goals and values of the project will be encouraged so that the interviewers will

wish to preserve its integrity by collecting accurate data.

4 - Equipment

(a) Automobiles

Six cars will be provided, one for each pair of interviewers and for the supervisor. These will be small compact cars.

E - Test Materials and Supplies

Each interviewer should have a small suitcase containing all of the test materials and equipment needed.

F - Photographic Supplies

The recording of the design and field work should be done pictorially as well as by written word. Pictures of the process will be extremely valuable in the later communication of the method and the findings.

G - The Selection and Training of Interviewers

Accuracy in selecting the people to go to P.E.I. will save much in the way of funds, time and effort. Therefore, considerable effort will go into the moulding of a competent group of psychometricians who can function optimally under what may, at times, be trying circumstances.

Selection will take place via a series of steps. The first will be to mail circulars to a variety of settings where suitable candidates are likely to be found. These might include graduate schools of education, psychology, social work and sociology and government mental health services. Written applications will be the first screening step. Personal

interviews will be the second. One month of intensive training will follow. It is hoped that this will take place in one of the other Maritime provinces, preferably New Brunswick.

The actual training procedures, which will last four weeks, will consist of a series of steps:

(i) Lectures: Potential interviewers should be cognizant of some of the theory and practice of psychological testing and on the background of the tests they are going to use.

(ii) Practice Test Administration: Interviewers will have practice in these procedures with other staff members as subjects.

(iii) Practice Testing in the Field: Interviewers will have additional practice in testing through entering homes and interviewing all family members.

(iv) Assigned Reading: Required reading on field work, testing, and on the Canadian Welfare Council project, will be given.

(v) Assessment: Candidates will be given a written test as a final step in assessing their competency and skill before they go into the field as interviewers.

VI - ANALYSIS OF THE DATA

The data processing for the proposed study will range from the application of some very simple techniques and steps to some rather sophisticated ones. In this section, they will all be spelled out so that the reader may have a complete picture of the steps to be taken and the procedures to be used.

A - Scoring

Four of the items in the data must be hand-scored. These will be scored by the interviewers while in the field; these items are: the WISC items, the Draw-A-Person Test, the socio-economic status index and the personal value responses.

B - Coding

All other data will be punched on to computer cards directly from the test protocols. Thus, the preparation of the data for the analyses may be carried out in stages, before all the data are collected Key punching will be done through facilities available in Ottawa.

C - Statistical Facilities

Computation will be carried out at one of the major data analysis centers in Ottawa, such as the University of Ottawa or Carleton University. Where necessary, in the case that programs are not available and working in Ottawa, the analyses will be done in the United States where such programs are available.

D - Statistical Techniques

The actual statistics to be used, best discussed under two headings, are those to be used for processing the data yielding the prevalence results and those to be used in processing the data in

order to obtain the analytical results.

I - Prevalence Results

The prevalence results will be presented in a series of tables based upon frequency distributions of the samples studied. These frequencies will be used to estimate the prevalence of the category under study in the total population. The probable error of estimate will be computed so that the accuracy of the resulting figures may be judged. For example, tables such as shown on page 40 will be presented. This section of the results, then will consist of little more than counting and compiling incidences by population category. The significance of the difference between categories where of interest, will be analyzed and statistical tests such as the Chi-squared statistics will be employed.

Examples of the tables which will be compiled include the following:

(i) The prevalence of mental retardation in P.E.I. classified by age, sex and degree of retardation.

(ii) The prevalence of mental retardation in P.E.I. classified by age, sex and ethnic background.

(iii) The prevalence of mental retardation in P.E.I. classified by age, sex and source of family income and employment.

(iv) The mentally retarded in P.E.I. classified by the type of treatment being received.

(v) The mentally retarded in P.E.I. classified by age and employment.

(vi) The mentally retarded in P.E.I. classified by type of retardation.

(vii) The mentally retarded in P.E.I. classified by their social abilities as reported by the mother or caretaker.

(viii) The mentally retarded in P.E.I. classified by county.

(ix) The intellectual performance levels of the aged in P.E.I.

(x) The prevalence of mental retardation in P.E.I. in bilingual families.

(xi) The prevalence of mental retardation in P.E.I. by religious affiliation.

(xii) The prevalence of mental retardation in P.E.I. classified by type of educational facility available to the population.

II - Analytical Results

Whereas the results in the previous section will serve to answer the questions and hypotheses surrounding the prevalence of retardation, the present section centers around explaining and defining the nature of retardation and disability in general. These results will both support and extend those in the preceding section.

(i) Item and Test Statistics

In order to argue upon the basis of accurate data, there are several analyses to be carried out in order to determine

the reliability and validity of the tests and measurements used for different groups of subjects. The statistics to be used are: inter-correlation of items, inter-correlation of subjects, measures of reliability and validity and homogenity indices.

(ii) Correlations between Continuous Variables Compared over Contrasting Groups

Correlational indices will be used in order to determine the association of variables across groups. For example, Is degree of religious belief highly correlated to understanding attitudes towards the retarded?

(iii) Factor Analyses

The Gough Socialization Scale will be factored, so that separate scores on the factors for each individual may be extracted. This will enable the holding of homogeneous dimensions of social attachment constant as independent variables, in order to find how attitudes (for example towards the mentally retarded) vary as a result.

(iv) Comparisons of Means between Subject Groups

Several techniques may be used to compare mean scores on various indices across subject groups (t-tests, sign tests, etc.) Examples of the type of problem to be investigated would be: do mothers of mentally retarded children experience fewer happy or unhappy feelings when the child lives in the home than when the child is removed from the home?

Do mentally retarded adults, due to their position at the extreme on the intellectual performance variables have any similarities in feelings and social attitudes with individuals who are intellectually superior?

In summary, the statistical analyses to be carrierd out are not complex. There will be no need to develop new methods to fit the needs of the present study. Rather the challenge here is from the extent of the data. There are many questions to be answered and a great many analyses to be carried out. However, once they are programmed and running, the labour or time of running them rather than the problem of applicability is the major one.

(v) The Use of Natural Control Groups and Replication

The conclusions made in the study will always be based upon (1) the direction of the numerical results and their significance, (2) upon comparisons with natural control groups from the general population and, (3) upon replication. It will always be possible to choose subgroups to test whether the results hold up. Thus major conclusions will be based upon trends, substantiated by several means and not only upon single test of significance.

VII - OVERVIEW

The specific purposes of the study have been stated in earlier sections of this proposal. The broader goals and purposes involve a statement which places the study in the current Canadian scene.

It may be noted that a study of this nature in mental retardation has not previously been carried out in this country. Few have been attempted anywhere. For this reason, the project stands to contribute much in findings and conclusions as well as in methodology and execution to other countries besides Canada. There is no reason why Canada should not lead in this important area of research.

The study will resolve several demanding issues in planning, care and treatment of the mentally retarded and disabled people in Prince Edward Island, and if extended, to all of Canada. The present orientation of the authors towards programmes, care and treatment is uncommitted. The intention is that the data be evaluated, rather than that pre-existing values and assumptions be used to fill in where facts are missing. Many professional and lay people deeply involved in the process of planning for the retarded will be needed, in turn, to evaluate the conclusions and recommendations, and to decide ultimately which will be implemented, which will be introduced on trial and which will be dismissed as impractical until a later time.

The study is launched with the belief that more social research is essential for the future planning of Canadian society.

It takes only time, care and hard work to carry out empirical studies in order to provide government officials with clear facts and substantial information upon which to base their decisions.

Government has already shown its concern for such research by making grants available for many purposes. Canada is currently well established in research in the physical sciences but lags in the production of research in some areas of the social sciences.

The present study is a large step in the field of mental retardation research. It is only a small step on the horizon of research in the social sciences. This proposal is submitted with the sincere hope that it will be one of a great many important strides in the further social development of the Canadian people.

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